## Congress of the United States Washington, DC 20515

February 15, 2022

Xavier Becerra, JD Office of the Secretary U.S. Department of Health and Human Services 200 Independence Avenue, SW Washington, DC 20201 Chiquita Brooks-LaSure
Office of the Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Rochelle P. Walensky, MD, MPH Office of the Director Centers for Disease Control and Prevention 1600 Clifton Road, NE Atlanta, GA 30333

Dear Secretary Becerra, Director Walensky, and Administrator Brooks-LaSure,

We write to express our concerns regarding the staggering long-term health effects of COVID-19, particularly on children under 18 years old. Policymakers, parents, and health officials alike have been alarmed by recent research published by the Centers for Disease Control and Prevention (CDC) that indicates children and adolescents who become infected with COVID-19 are at increased risk of receiving a new Type 1 diabetes diagnosis. We urge the Department of Health and Human Services to take immediate action to improve the healthcare system to support and monitor children as the long-term effects of COVID-19 continue to harm them.

We are currently in the midst of a historically unprecedented threat to life, health, and safety as we head into the third year of a deadly pandemic. The US reported 1.5 million new cases in a single day on Jan. 11,<sup>2</sup> adding to the staggering 78 million positive cases and over 915,000 preventable deaths reported since March 2020.<sup>3</sup> For example, in St. Louis, communities are grappling with the impact of a nearly 40 percent peak positivity rate that threatens to disrupt every sector of our local economy.<sup>4</sup> Children in particular have faced tremendous obstacles while navigating the pandemic, ranging from the tragic loss of parents and caregivers, difficult school closures, and the constant threat to life and health.

We urge the Department of Health and Human Services and the agencies within to take the following actions:

Immediately issue guidance to local, state, and federal health officials emphasizing the need for drastically increased health monitoring of children during and after a COVID-19 infection, and to make data available on the CDC website.

<sup>&</sup>lt;sup>1</sup> https://www.cdc.gov/mmwr/volumes/71/wr/mm7102e2.htm

<sup>&</sup>lt;sup>2</sup>https://www.cnbc.com/2022/01/11/omicron-variant-us-sets-fresh-records-for-covid-hospitalizations-and-cases-with-1point5-million-new-infections.html

 $<sup>\</sup>frac{3}{\text{https://ourworldindata.org/explorers/coronavirus-data-explorer?tab=table&facet=none&Metric=Confirmed+cases&Interval=Cumulative&Relative+to+Population=false&Color+by+test+positivity=false&country=USA~ITA~CAN~DEU~GBR~FRA~IPN}{\text{Interval}}$ 

<sup>4</sup> https://fox2now.com/news/you-paid-for-it/st-louis-health-commissioner-reports-highest-positivity-rate-since-pandemic-started/

Until October 29, 2021, children aged 5 through 11 were unable to rely on the protection of vaccines,<sup>5</sup> despite the reopening of schools and workplaces in August 2021 and children under 12 could not be fully vaccinated and protected from COVID-19 until at least November 19, 2021—months after the majority of schools reopened in accordance with CDC K-12 guidance.<sup>6</sup> Currently, children under 5 cannot receive the vaccine, rendering them extremely vulnerable while the Omicron variant tears through our communities unfettered. According to the American Academy of Pediatrics, over 12 million children have tested positive for COVID-19 since the onset of the pandemic.<sup>7</sup>

Since the first week of September 2021—directly corresponding with school reopenings—there have been over 7 million additional positive COVID-19 cases in children.<sup>8</sup> This data is particularly alarming in light of the long-lasting implications of this illness being discovered nearly every day. As you may know, long COVID is becoming an increasingly concerning phenomena for patients around the world who are still dealing with the devastating impact of COVID-19, months or even years after being infected. Researchers conservatively estimate that between 10 and 30 percent of people who get Covid-19 will suffer from long COVID symptoms.<sup>9</sup>

Based on these staggering numbers of children exposed to COVID-19, we ask that the CDC release detailed guidance for the monitoring of children's health during and after the pandemic. Further, we urge the CDC to ensure this guidance provides for adequate health monitoring of children for Type 1 diabetes, long COVID, and other conditions associated with COVID-19 as they are discovered.

## Remove cost barriers to post-COVID monitoring and care.

Guidance from the CDC on best practices for increased monitoring of children during and after the pandemic is necessary but due to the entrenched inequities in our health system is not sufficient to protect all children. We urge the Centers for Medicare and Medicaid Services (CMS) to remove all barriers to this care such as cost, geographic location, and socioeconomic status. Centering health equity in post-COVID monitoring and care is crucial to recovery from the pandemic.

## Use all available authorities to make drugs needed by those suffering from COVID-19 long-term effects available to everyone.

While medical experts are still discovering the extent of long COVID, the CDC has confirmed coronavirus can impair numerous organs, including the heart, lungs, skin, kidneys, and brain. Studies suggest that long COVID affects children with the same wide and disturbing range of symptoms as adults, from heart palpitations and "brain fog" to difficulty breathing and painful

<sup>10</sup> *Id*.

<sup>\$</sup>https://www.fda.gov/news-events/press-announcements/fda-authorizes-pfizer-biontech-covid-19-vaccine-emergency-use-children-5-through-11-vears-age

https://www.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/children-and-covid-19-state-level-data-report/

<sup>°</sup> Id.

<sup>9</sup> https://www.rollingstone.com/culture/culture-features/long-covid-19-research-data-omicron-1284218/

rashes.<sup>11</sup> Approximately half of the children treated at the Kennedy Krieger Institute's long COVID clinic in Baltimore suffer from anxiety or depression.<sup>12</sup> It is clear that COVID-19 increases the need for long-term healthcare services and medications. However, the extremely high cost of medications like insulin prevent untold numbers of long COVID patients from accessing adequate medical care, particularly patients with no insurance.

We urge the Department of Health and Human Services (HHS) to make overpriced medications needed by these patients affordable by using the existing authorities including march-in rights under the Bayh-Dole Act and compulsory licensing under Title 28, U.S. Code Section 1498. The pharmaceutical price gouging crisis will only worsen as more people require medication to treat the long-term effects of COVID-19 making it more important than ever to reign in drug prices. In cases where march-in rights and compulsory licensing are not adequate, such as insulin, we urge HHS to develop a public manufacturing option for those drugs.

The impact of potentially millions of children becoming permanently impaired from COVID-19 will have unforeseeable consequences unless policymakers immediately intervene. Given that human life and health are at risk, it is imperative that HHS remain a consistent and reliable steward of public health that presents a comprehensive, rapid federal response to controlling the spread of COVID-19. Beyond preventing the spread of disease, it is within the purview of the Centers for Disease Control to help communities mitigate the damaging effects the virus leaves in its wake. Working in concert, CMS must assure that these monitoring and care services are available to all regardless of ability to pay. Finally, HHS must ensure that if health problems are uncovered thanks to increased monitoring, that patients can afford the medications needed to treat their conditions.

While we were relieved to see the Department of Health and Human Services officially declare long COVID a disability under the Americans with Disabilities Act (ADA) in July 2021, <sup>13</sup> there is considerable work to be done to support this newly-disabled population. Lawmakers, local and state health officials, and impacted advocates alike are eager to work closely in coordination with the HHS to finally bring an end to this pandemic and support those who have been irreparably harmed by this virus.

Thank you for taking our recommendations into consideration. We look forward to supporting and bolstering HHS, CDC, and CMS's efforts to implement a comprehensive federal approach to this deadly public health emergency and its long-term effects.

Sincerely,

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 $<sup>^{11}\ \</sup>underline{https://www.aamc.org/news-insights/scary-and-confusing-when-kids-suffer-long-covid-19}$ 

<sup>&</sup>lt;sup>12</sup> *Id*.

<sup>13</sup> https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html#footnote10 0ac8mdc

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